



STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
Honolulu, HI 96801-3378
doh.testimony@doh.hawaii.gov

**Testimony COMMENTING on HB 467 HD 1
RELATING TO HEALTH**

REPRESENTATIVE ANGUS L.K. MCKELVEY, CHAIR
HOUSE COMMITTEE ON CONSUMER PROTECTION AND COMMERCE
Hearing Date: February 11, 2015 Room Number: 325

Fiscal Implications: None. The added data collection, analysis, and dissemination activities will be absorbed by the current Newborn Metabolic Screening Program staff and resources.

Department Testimony: The Department of Health supports the intent of this bill to mandate birthing facilities to do newborn screening for Critical Congenital Heart Defects (CCHD) using pulse oximetry or another method recommended by the American Academy of Pediatrics, and to provide newborn CCHD screening data to the Department of Health for quality assurance and improvement activities.

Data collection and information dissemination for quality improvement is needed. The algorithm and methodology for CCHD screening is not evidence-based but rather the best guess of a group of experts. Therefore, data need to be collected from real time screening of newborns with the outcomes to support and/or refine the methodology. This quality improvement activity is a required process especially in a state with a low birth rate like Hawaii and will allow Hawaii to participate in the national effort to refine and improve the methodology for CCHD screening. Data are also needed to help birthing facilities recognize potential problems with their CCHD screening that may cause inaccurate results.

The national incidence of CCHD is 2/1000 births. National and local pediatric cardiologists report that about 50% of the cases are detected prenatally. Some cases will have symptoms at birth. Best estimates are that about 1/2000 newborns with CCHD are asymptomatic and may be detected using pulse oximetry screening. With Hawaii's birth rate, screening could detect approximately 10 asymptomatic newborns with CCHD per year.

Thank you for the opportunity to testify on this measure.



American Heart Association testimony in strong SUPPORT of HB 467, HD1 “Relating to Health”

The American Heart Association strongly supports HB 467, HD1 “Relating to Health.”

Congenital heart defects (CHD) are the most common birth defect in the U.S. and the leading killer of infants with birth defects. In the US, about 7,200 (or 18 per 10,000) babies born each year have one of seven critical congenital heart defects (CCHDs). An estimated 300 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States. These babies are at risk for having serious problems within the first few days or weeks of life and often require emergency care.

Pulse oximetry newborn screening can identify some infants with a CCHD before they show any signs. Once identified, babies with a CCHD can be seen by cardiologists (heart doctors) and can receive specialized care and treatment that could prevent death or disability early in life. Treatment can include medications and surgery.

One of the best ways to detect CCHD is through a simple, noninvasive, inexpensive test, called **pulse oximetry**, or pulse ox. The pulse ox test consists of sensors placed on a baby's hand and/or foot to check blood oxygen levels. It is a simple bedside test to determine the amount of oxygen in a baby's blood and the baby's pulse rate. Low levels of oxygen in the blood can be a sign of a CCHD. The test is done using a machine called a pulse oximeter, with sensors placed on the baby's skin. The test is painless and takes only a few minutes.

If the baby's levels are too low, additional tests may be conducted. New research suggests wider use of pulse ox screening would help identify more than 90 percent of heart defects, with costs of the testing estimated at below \$4 per baby.

In September 2011, U.S. Secretary of Health and Human Services Kathleen Sebelius suggested that critical congenital heart defects screening be added to the “Recommended Uniform Screening Panel” for newborns before they are released from a hospital or birthing facility. To achieve this goal efforts are underway across the country to enact pulse ox screening policies that will allow babies with heart defects to live longer and fuller lives. At the time of this hearing, at least 35 states have passed legislation requiring pulse ox screening for all newborns. Others are expected to follow suit this year. Hawaii remains in the minority of those that currently don't require the screening.

HB 467, HD1 would help to insure that all Hawaii families are provided with the most recent standard of care-based health screenings for their newborns. The AHA urges Hawaii legislators support HB 467, HD1.

Respectfully submitted,

Donald B. Weisman
Hawaii Government Relations Director

*“Building healthier lives,
free of cardiovascular
diseases and stroke.”*

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Please remember the American Heart Association in your will.



Date: February 10, 2015

To: Representative Angus McKelvey, Chair
Representative Justin Woodson, Vice Chair

From: Lin Joseph
Director of Program Services
March of Dimes Hawaii Chapter

Re: In support of
HB467 HD1
Hearing: Wednesday, February 11, 2015
Conference Room 325, State Capitol

March of Dimes Foundation

Hawaii Chapter
1580 Makaloa Street, Suite 1200
Honolulu, HI 96814
Telephone (808) 973-2155
Inter-island 1-800-272-5240
Fax (808) 973-2160

marchofdimes.com/hawaii

Chair McKelvey, Vice Chair Woodson, Members of the Committees:

I am writing to express support for HB467 HD1: *Relating to Critical Congenital Heart Defects Newborn Screening*.

The March of Dimes is the leader in advocacy for newborn screening of all infants in the United States. Our mission is to *improve the health of babies by preventing birth defects, premature birth, and infant mortality*. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. In 2009, March of Dimes presented the state of Hawaii with the March of Dimes National Award for Excellence in Newborn Screening for being a leader in screening newborn infants for all 29 disorders recommended at that time by the American College of Medical Genetics.

In 2011, the Secretary of the U.S. Department of Health and Human Services added critical congenital heart disease (CCHD) to the Recommended Uniform Screening Panel. CCHD is a subgroup of congenital heart defects which are problems with the heart's structure and/or function that are present at birth. "Critical" indicates that the heart defect causes severe, life threatening symptoms that require intervention, such as medical treatment or surgery, within the first hours, days or months of life. Unlike screening for metabolic disorders which utilizes a few drops of blood from a newborn's heel, CCHD, cannot be detected through blood spots and is sometimes difficult to detect by physical exam and observation. Currently, CCHD can be detected through pulse oximetry to measure the percent of oxygen saturation of hemoglobin in the arterial blood using a sensor attached to the infant's finger or foot. This screening provides that, should a newborn screen positive for CCHD, diagnostic tests can be administered before the infant's symptoms are evident and allow for early interventions to improve outcomes.

HB467 HD1 will establish newborn screening to detect CCHD to ensure that newborns in Hawaii are screened for congenital heart conditions that, if undetected, can be severe and life-threatening. Mahalo for the opportunity to testify in support of HB467 HD1.



Wednesday – February, 11, 2015; 2:30 pm
Conference Room 325

HOUSE COMMITTEE ON CONSUMER PROTECTION & COMMERCE

Representative Angus McKelvey, Chair
Representative Justin Woodson, Vice Chair

From: Charles Neal, Jr., MD, PhD
Chief, Neonatology Department

Re: HB 467, HD1 Relating to Health
Testimony In Support

My name is Dr. Charles Neal, Jr., MD, PhD and I am the chief of the Neonatology Department of Kapi'olani Medical Center for Women & Children (Kapi'olani). Kapi'olani Medical Center is the state's only maternity, newborn and pediatric specialty hospital. It is also a tertiary care, medical teaching and research facility. Specialty services for patients throughout Hawai'i and the Pacific Region include intensive care for infants and children, 24-hour emergency pediatric care, air transport, maternal-fetal medicine and high-risk perinatal care. The not-for-profit hospital offers several community programs and services, such as the Kapi'olani Child Protection Center and the Sex Abuse Treatment Center. Additionally, Kapi'olani's Women's Center is ranked among the top in the nation. Kapi'olani Medical Center is an affiliate of Hawai'i Pacific Health, the state's largest health care provider.

I am writing in support of HD 467, HD1. This measure requires that birthing facilities perform a critical congenital heart defect screening using a pulse oximetry on every newborn in its care prior to discharge. The pulse oximetry is a non-invasive test that is an effective means of detecting critical, life-threatening congenital heart defects which may otherwise go undetected by current screening methods.

Kapi'olani Medical Center for Women & Children (Kapi'olani) has long followed the Academy of Pediatrics (AAP) guidelines which recognizes the importance of screening for congenital heart defects. We have established and apply pulse oximetry screening as the standard of care for all newborns to screen for congenital heart disease.

Thank you for the opportunity to provide this testimony.

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 09, 2015 8:55 AM
To: CPCtestimony
Cc: wojo.cari@gmail.com
Subject: Submitted testimony for HB467 on Feb 11, 2015 14:30PM
Attachments: Keiki Heart Bill testimony.docx

HB467

Submitted on: 2/9/2015

Testimony for CPC on Feb 11, 2015 14:30PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Cari Ann Csigi	Individual	Support	No

Comments:

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

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I am writing in support of the Keiki Heart Bill. My family and I have supported this bill from the beginning. We have been affected by congenital heart defect. Our son, Shayden, was born with a congenital heart defect. His condition was not detected until one week after his birth. He was then immediately medivaced to California, where he spent months in the hospital. He went through many procedures, surgeries, and tests. He also went into cardiac arrest. During his stay in the hospital, Shayden contracted multiple infections. In November 2011, Shayden's body could not handle any more. He passed away at four months old.

Supporting this bill not only gives us a chance to speak out about our experience, but it also gives us a chance to fight for our son and many other families. We have met families whose babies' defects were detected after being sent home. Those families are still fighting to this day. Passing this bill will help doctors treat these babies immediately. Children are our future, they deserve a fighting chance in life. If Shayden had pulse oximetry screening done, he may be alive today. Please give children the chance in life that my son didn't have.

Thank you